



VOICE OF THE DIABETIC

A SUPPORT AND INFORMATION NETWORK
The Diabetics Division of the National Federation of the Blind

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Page 1

Neuropathy need not limit independent travel

by Amy Walters



Amy Walters (shown with guide dog Jingles) has experienced nerve damage from diabetes, but does not let it slow her down.

Neuropathy is something we diabetics all must confront. For some of us it will be more or less severe, and in my case it led to blindness. However, I have not let it limit me. Hopefully my experiences can show the alternatives.

At the age of 21, after having had diabetes for 15 years, I was losing my sight. The year was 1980 and, at that time, the doctors were not quite sure what was happening. They assured me that I would not lose vision entirely, and that if I lost some, I would likely regain it. After several surgeries and laser treatments, I found myself totally blind.

Five months at the Vision Center, an in-house rehabilitation agency, helped me learn how to cope with blindness and helped restore my con-

fidence. Life was not over simply because I could no longer see.

One of my biggest challenges was getting around independently. I soon found out that, along with the blindness, I had neuropathy in both feet. Neuropathy, decrease of sensation due to nerve damage, was new to me, but I quickly became aware of its ramifications.

My first lesson with my mobility instructor was a total disaster. Cane in hand, I fell badly after only a few steps, my feet unable to pick up the subtle variations in the pavement. It was a very negative experience.

It was at that time, while I was learning about traffic patterns, sound cue landmarks, and building up my strength, that the Vision Center suggested I consider a guide dog.

After my five-month stay, I returned home, to receive orientation instruction in my own area. My new instructor soon discovered that not only was I unable to detect sidewalk variations with a cane, I veered to the left, the result of a childhood fracture of the left ankle. This instructor also recommended a guide dog, noting that the dog would keep me moving in a

straight line.

The Seeing Eye School was recommended to me, and after applying and sending in all the necessary paperwork, I waited for an opening. One day I received a call from the director of training. He was going to be in my area, and asked if we could meet and go for a "Juno walk." Not sure what that was, I agreed anyway.

It turned out "Juno" was the instructor, who held a special harness. I was to command him as I would a guide dog. I grasped the handle at the other end, and away we went. The sight we

(Continued on page 15)

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Voice of the Diabetic is a national publication of The Diabetics Division of the National Federation of the Blind. It is read by those interested in all aspects of blindness and diabetes. We show diabetics that they have options regardless of the ramifications they may have had. We have a positive philosophy and know that positive attitudes are contagious!

News items, change of address notices and other magazine correspondence should be sent to:

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HCFA response to Diabetes Division inquiries regarding Medicare blood glucose monitor reimbursement

by Ed Bryant

On May 20, 1993, I wrote to Health and Human Services Secretary Donna Shalala, bringing to her attention the difficulties blind diabetics and those losing vision often experience when trying to obtain Medicare reimbursement for purchase of glucometers. The letter was published in the summer 1993 edition of *Voice of the Diabetic*.

Members of The Diabetes Division of the National Federation of the Blind in many states helped research this project. All capable men and women, they encountered numerous examples of official misinformation and departures from stated guidelines and regulations.

On July 23, 1993, Kathleen A. Buto, Director of Bureau of Policy Development, Health Care Financing Administration of the Department of Health and Human Services, delivered Secretary Shalala's official reply. The letter contained much useful information, and is reprinted in its entirety below. Unfortunately, some questions were not clearly or completely addressed, and some information (such as fee schedules for Alaska and Hawaii) was entirely absent.

Director Buto refers to the Medicare "fee schedule," and to "weighted averages." The fee schedule is the stipulated range of costs established under Medicare Part B as a basis for reimbursement for purchase of durable medical equipment. E0609 is the HCFA specification for a blood glucose monitor with audio output. E0607 is the HCFA specification for a blood glucose monitor without audio output.

1. E0609:
The National CEILING is \$467.74
The National FLOOR is \$397.58
Ceiling Reimbursement = 80% of
\$467.74 = \$374.19
Floor Reimbursement = 80% of
\$397.58 = \$318.06

2. E0607:
The National CEILING is \$191.05
The National FLOOR is \$162.39
Ceiling Reimbursement = 80% of
\$191.05 = \$152.84
Floor Reimbursement = 80% of
\$162.39 = \$129.91

Federal law requires the actual cash reimbursement for equipment purchased under E0609 or E0607 to fall within their above reimbursement ranges. Note that Medicare reimburses at 80% of the "approved amount," in the range between National Ceiling and National Floor figures.

The "weighted average" is the local average cost for a given item or type and is equal to the fee schedule ceiling. Weighted averages (and thus fee schedules) are determined state by state, but MUST fall within the national range, as listed in tables 1 and 2 above.

Following Director Buto's letter will be my Aug. 11, 1993 reply to her. As of press time, Sept. 27, we have received no response.

Department of Health and Human Services
Health Care Financing Administration
Baltimore, MD
July 23, 1993

Mr. Ed Bryant
National Federation of the Blind
Columbia, MO

Dear Mr. Bryant:

Secretary Shalala asked me to thank you for your inquiry regarding Medicare payment for blood glucose monitors, codes E0607 (home blood glucose monitor) and E0609 (blood glucose monitor with special features [e.g., voice synthesizers, automatic timer, etc.]) in the Health Care Financing Administration (HCFA) Common Procedure Coding System (HCPCS).

Medicare policy regarding payment for blood glucose monitors and other covered items of durable medical equipment (DME) was changed by section 4062 of the Omnibus Budget Reconciliation Act (OBRA) of 1987 (Public Law 100-203) which amended the Social Security Act at section 1834(a). This section completely restructures the previous reasonable charge payment methodology by providing for the calculation of fee schedule amounts to pay for DME. Subject to coinsurance and deductible amounts, payment is limited to the lower of the actual charge for the item or the fee schedule developed for the class of equipment that contained the item. Blood glucose monitors are located in the inexpensive or routinely purchased class of DME. This provision of OBRA of 1987 was initiated and heavily supported by organizations representing DME suppliers.

As required by section 4062, the fee schedules for codes E0607 and E0609, and all other inexpensive or routinely purchased items of DME are based on the average Medicare allowed charges from the base year period of July 1, 1986 through June 30, 1987, plus a 1.7 percent update for 1989 and all cumulative covered item updates assigned by Congress. For 1993, the covered item update is 3.1 percent.

Section 4152 of OBRA of 1990 (Public Law 101-508) provides for the calculation of national fee schedule floors and ceilings for inexpensive or routinely purchased items of DME. The fee schedule floor for a given item is equal to 85 percent of the weighted average of the local fee schedule amounts for that item. The fee schedule ceiling is equal to the weighted average of the local fee schedule amounts for that item.

The following are our responses to
(Continued on page 4)

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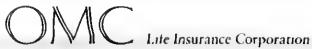
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HCFA response to Diabetics Division inquiries regarding Medicare blood glucose monitor reimbursement

(Continued from page 3)

your questions and requests listed on pages 8 through 10 of your inquiry:

(Editor's Note: The questions to which Ms. Buto is responding were published in the Summer 1993 Voice. For clarity, each question is restated immediately above her answer.)

O: Please send a list showing the state-by-state approved amounts for Medicare Procedure Codes E0607 and E0609. Currently it is impossible to ascertain if eligible recipients are receiving the amounts listed in HCFA guidelines.

1. The following are the Medicare fee schedules for the purchase of new blood glucose monitors:

1993 DME FEE SCHEDULES - BLOOD GLUCOSE MONITORS

STATE	E0607	E0609
AL	\$165.60	\$397.58
AR	\$178.71	\$467.74
AZ	\$180.76	\$467.74
CA	\$191.05	\$397.58
CO	\$169.76	\$467.74
CT	\$169.59	\$467.74
DC	\$166.39	\$467.74
DE	\$166.12	\$397.58
FL	\$191.05	\$460.79
GA	\$170.00	\$397.58
IA	\$188.61	\$467.74
ID	\$174.90	\$453.31
IL	\$191.05	\$467.74
IN	\$162.39	\$397.58
KS	\$191.05	\$467.74
KY	\$191.05	\$467.74
LA	\$180.39	\$467.74
MA	\$165.24	\$467.74
MD	\$168.61	\$467.74
ME	\$165.24	\$467.74
MI	\$191.05	\$397.58
MN	\$166.74	\$467.74
MO	\$191.05	\$467.74
MS	\$191.05	\$467.74
MT	\$165.33	\$467.74
NC	\$171.32	\$467.74
ND	\$186.02	\$467.74
NE	\$191.05	\$467.74
NH	\$165.24	\$467.74
NJ	\$167.31	\$467.74
NM	\$191.05	\$467.74
NV	\$191.05	\$467.74
NY	\$191.05	\$467.74
OH	\$182.43	\$467.74
OK	\$191.05	\$467.74
OR	\$165.50	\$397.58
PA	\$162.39	\$397.58
RI	\$175.39	\$467.74
SC	\$191.05	\$467.74
SD	\$191.05	\$467.74
TN	\$180.81	\$467.74
TX	\$191.05	\$397.58
UT	\$191.05	\$397.58
VA	\$168.22	\$467.74
VT	\$165.24	\$467.74
WA	\$187.99	\$467.74
WI	\$163.76	\$397.58
WV	\$186.83	\$467.74
WY	\$177.19	\$467.74

Q: Is there an official reference pamphlet/booklet for purchasers of blood glucose monitoring equipment? Consumers covered by Medicare need access to the regulations. (As I've mentioned, some suppliers have only a small portion of the information from the reference manual.)

2. There are no HCFA publications for purchasers of blood glucose monitoring equipment.

Q: Sometimes blind diabetics, as well as many other consumers, receive incorrect or contradictory information from Social Security and Medicare offices. What can be done to eradicate dissemination of incorrect information? Numerous examples are listed in the text. Why are consumers being told that information isn't available, or is only available with a prescription or some other requirement?

3. Please see our answers to similar questions below.

Q: My data show that Medicare has not given the same kind of consideration to equipment for the blind as it has for the sighted. The national average cost for E0607 is \$89.63, which is \$101.42 BELOW the fee schedule ceiling. Yet the national average cost for E0609 is \$522.50 which is \$54.76 ABOVE the fee schedule ceiling! What can be done to correct this situation, which is not fair to blind citizens?

4. In 1986, charges for standard home blood glucose monitors (E0607) were generally in excess of \$150. Current fee schedule amounts for E0607 accurately reflect the average allowed charges for E0607 in 1986, adjusted by 1.7 percent (the percentage increase in the CPI-U for the 6-month period ending with December 1987), and updated by 3.7 percent (the 1991 covered item update), 3.7 percent (the 1992 covered item update), and 3.1 percent (the 1993 covered item update).

Due to advances in technology, home blood glucose monitors are now available at prices far below the current fee schedule amounts for E0607. In the event that the fee schedule calculation methodology produces grossly deficient or grossly excessive fee schedule amounts for a given item or category of items, HCFA is authorized by section 1834(a)(10)(B) of the Social Security Act to apply special payment limits, commonly referred to as inherent reasonableness (IR) limits, for such an item(s) on a national basis. HCFA is currently in the process of drafting a proposed notice that would establish a national IR limit for E0607. HCFA must publish all proposed IR limits in the Federal Register, allowing no less than 60 days for public comment.

(Continued on page 8)

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Blind diabetics can draw insulin without difficulty

by Ed Bryant



Editor Ed Bryant says, "Thousands of blind diabetics have proven you CAN independently self-manage your diabetes."

A major aim of The Diabetics Division of the National Federation of the Blind (NFB) is to provide support and information for blind diabetics, so that they might better maintain or regain independence and productiveness. Our national network allows division members and their families to communicate across a wide area, something important for blind diabetics and those

losing vision. With all the trauma of sight loss, sometimes the newly blinded diabetic does not realize that most blind men and women with diabetes CAN self-manage their diabetes safely and accurately, by use of alternative techniques.

I have had diabetes for thirty-four years. I became blind due to diabetic retinopathy about fifteen years ago. When I first became blind, I didn't use measuring devices to draw my insulin. I had never HEARD of insulin gauges! Twelve years ago, I designed my own insulin gauge, and I used it for approximately three years, with no difficulties. I do not advocate the use of non-standard or homemade insulin-measuring devices by blind diabetics, unless ALL equipment has been checked out by the health care team, or by someone knowledgeable in insulin-measuring techniques.

Members of the health care community sometimes forget that although a diabetic may be newly blinded, he or she has often been dealing with the disease for fifteen years or more. Most long-term Type I diabetics have had years of experience drawing their own insulin.

Because of my experience with diabetes and blindness and my editorship of *Voice of the Diabetic*, I am

often asked to evaluate insulin-measuring gauges designed for the blind or visually impaired. I have tested numerous measuring devices, and in my opinion the Count-A-Dose, from Jordan Medical Enterprises, wins the blue ribbon. I hasten to add that no one instrument is ideal for everyone; however, the Count-A-Dose provides a very easy method of insulin dispensing. Designed for the Becton-Dickinson LoDose syringe, the Count-A-Dose holds two insulin vials and directs the syringe needle into the vials' rubber stoppers. Using the thumbscrew adjuster, which clicks for each one unit measured, the blind diabetic can quickly and reliably draw and mix his or her own insulin.

How to Get Air Bubbles Out of an Insulin Syringe

There are techniques by which a blind diabetic may draw and mix insulin without air bubbles. I have used them successfully for the past several years. My daily treatment regimen is two injections using regular and NPH [Humulin] insulins. I first draw several units of regular insulin into the syringe and then inject all of it back into the vial. Then I draw several more units than I did during the first drawing and inject it all back into the vial. During the third drawing, I draw even a few more units, and return it to the vial. After repeating this procedure three or four times, I flick the syringe near the hub with my fingernail to expel any air present. I then slowly draw the full amount of insulin needed from the vial. When I draw insulin from the second vial, I draw the exact amount needed. I have had this checked several times and there have never been air bubbles present. Air that is in the syringe or needle is expelled during the procedure used with the first vial of insulin. I occasionally demonstrate this technique to nurses, who are delighted to see that air bubbles are not present and the insulin measurement is accurate. Of course long-term insulin users will be familiar with the need to inject as much air into the vial as the amount of insulin they withdraw, to facilitate getting the insulin into the syringe. For further information, consult with your doctor.

How to Know When an Insulin Vial is Getting Low

Each vial of insulin contains 10cc, 1000 units. Many methods exist that can be used to determine how long a supply will last. When I open a new vial of insulin, I carefully calculate how many days that particular bottle should last. I use a total of twenty units of regular insulin daily. If I divide the 1000 units (10cc) of a new insulin vial by the twenty units I use daily, one supply should last me about fifty days. In drawing out the insulin, I take care not to inadvertently draw out air. Also, as a safeguard, I assume that the new bottle contains only 900 units (9cc), which will last forty-five days instead of the fifty. As long as at least sixty units of insulin remain in the vial and it is kept in a straight up-and-

down position while drawing out insulin, the needle will remain submerged, and there is no danger of drawing air. One method of keeping track of the amount of insulin in the container is to set aside the number of syringes that will be needed for 900 units of insulin. Another might be to employ Braille, large print, tape recorders or personal computers. Before using the insulin, the vial can be shaken gently. With practice, it is easy to determine whether it is full, half full or nearly empty.

Discarding Vials of Insulin that Have 60 to 100 Units Remaining

After starting a new supply, the insulin in the old vial can be drawn out and transferred. This will save money. Caution: After a period of transferring insulin, the product may become outdated and unusable. Be sure that the insulin being transferred has not expired.

The Possibility of Inserting a Needle into a Blood Vessel

Since injection sites are in fleshy areas, and the insulin needles are short, chances of inserting a needle into a blood vessel are minimal. The worst that can be done is to hit a small capillary. Hitting a capillary would result in a small area becoming infused with blood. This is called a hematoma. Again, it is unlikely that the needle will be inserted into a small blood vessel. The amount of insulin entering the bloodstream via a capillary would be insignificant and would cause no harm.

Something to Think About

I periodically have my insulin gauge checked for accuracy; it has always measured precisely. If the diabetic is careful, difficulty in measuring insulin will not be encountered. I have found that inaccuracy is often the result of haste or carelessness.

It is reported that insulin gauges are more accurate than sight. When the plunger is pushed firmly to the gauge, the same amount of insulin will be obtained every time. Sometimes my sighted friends make errors in drawing insulin. Perhaps they would be more accurate if they used insulin gauges. Note: Syringes are mass-produced. Although there is quality control, some errors are made in syringe markings. If a gauge is used, the measurement will be accurate no matter what the syringe shows.

I have no problems managing and keeping my diabetes under control. I am able to control my diabetes through the use of alternative techniques which many members of our organization, the National Federation of the Blind, use daily to live active lives. Many alternative techniques are utilized by blind diabetics, enabling them to be just as productive as when they were sighted.

Come to us and ask for assistance. We are ready, willing, and able to help. We in the National Federation of the Blind know that blindness is not synonymous with inability.

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HCFA response to Diabetics Division inquiries regarding Medicare blood glucose monitor reimbursement

(Continued from page 4)

ments on the proposed limits. HCFA must also publish all final IR limits in the Federal Register.

In the case of E0609, it has not been determined that the fee schedule amounts for this code are grossly deficient or grossly excessive. Based on the current pricing information that you supply in your inquiry, the 1993 fee schedule amounts for E0609 exceed the retail cost for one of the two available brands of blood glucose monitors with voice synthesizers.

Q: Why do some insurance carriers deviate greatly from the established Fee Schedule ceiling and floor? Is HCFA aware of this problem? What will you do to eradicate this disparity?

5. We are not aware of any such cases. Listed below are the addresses of all HCFA Regional Offices and the states for which they are responsible. Documentation of specific cases that carrier payments deviate greatly from established fee schedules may be submitted to the appropriate Regional Office for investigation. Beneficiaries should include a copy of the carrier's "Explanation of Medicare Benefits" (EOMB) form in the documentation.

Jurisdiction/States — Regional Office

CT, MA, ME, NH, RI, VT —
HCFA Boston Regional Office
John F. Kennedy Federal Building
Room 2325
Boston, Massachusetts 02203-0003

NJ, NY, PR —
HCFA New York Regional Office
26 Federal Plaza, Room 3811
New York, New York 10278-0063

DE, DC, MD, PA, VA, WV —
HCFA Philadelphia Regional Office
3535 Market Street, Room 3100
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AL, FL, GA, KY, MS, NC, SC, TN —
HCFA Atlanta Regional Office
101 Marietta Street, Suite 701
Atlanta, Georgia 30323-2711

IL, IN, MI, MN, OH, WI —
HCFA Chicago Regional Office
105 W. Adams Street
14th - 16th Floors
Chicago, Illinois 60603-6201

AR, LA, NM, OK, TX —
HCFA Dallas Regional Office
1200 Main Tower Building,
Room 2000
Dallas, Texas 75202-4305

IA, KS, MO, NE —
HCFA Kansas City Regional Office
New Federal Office Building
601 East 12th Street, Room 233
Kansas City, Missouri 64106-2808

CO, MT, ND, SD, UT, WY —
HCFA Denver Regional Office
Federal Office Building
1961 Stout Street, Room 1185
Denver, Colorado 80294-3538

AZ, CA, HI, NV —
HCFA San Francisco Regional Office
75 Hawthorne Street
4th and 5th Floors
San Francisco, California 94105-3903

AK, ID, OR, WA —
HCFA Seattle Regional Office
2201 Sixth Avenue
Mail Stop RX 40
Seattle, Washington 98121-2500

Q: Are your people aware that, as per "HCFA Coverage Issue Manual #6," Section 60-11: "Lancets, reagent strips, and other supplies necessary for the proper functioning of the device [home blood glucose monitor] are also covered for patients for whom the device is indicated?"

6. Yes we are aware that supplies used with home monitors are covered.

Q: On April 27, 1993, Medicare's Missouri Professional Relations Office reported an approved amount of \$202.96 for E0607. This figure does not comply with the fee schedules. What can be done to ensure that accurate, up-to-date information is dispensed by Medicare offices?

7. Documentation of specific cases of erroneous information from Medicare carriers should be reported to the appropriate Regional Offices listed above. Occasional errors will occur. If the problem is more frequent, the Regional Office will see corrective action.

Q: Are Fee Schedule increases mandated? If so, when will the increases occur?

8. The DME fee schedules are increased annually by a covered item update factor provided by Congress through legislation. Updates are generally effective January 1 each year.

Q: Because the Fee Schedules are already known, why is it easier to obtain information on nontalking blood glucose monitors than on monitors with audio output?

9. Completes fee schedule information has been furnished in response to Question 1.

Q: Some Medicare offices will divulge

amounts and others will not; some provide official figures and others provide incorrect figures or say they don't have the information. Why does this situation exist and what can you do to correct it? Why the hesitancy to dispense information to consumers?

10. Documentation of specific cases of the failure of a Medicare carrier to provide public information should be reported to the Regional offices listed above for investigation and appropriate corrective action.

Q: In the event that a consumer is in conformity with all rules and regulations, yet still does not receive the correct reimbursement, what courses of action are open to that consumer?

11. Information regarding how Medicare beneficiaries can appeal decisions made by carriers on Medicare Part B claims is provided on each EOMB. You may wish to read the more detailed explanation on page 36 of the Medicare 1993 Handbook (enclosed). This handbook may be obtained by Medicare beneficiaries by contacting the local district office of the Social Security Administration.

Q: Are Texas, Georgia and other such states in violation of the law regarding the fee schedule for E0609?

12. Again, we recommend that the detailed documentation of specific cases that show carrier error be submitted to the appropriate Regional Office for investigation and follow up.

Q: Blind consumers often experience considerable difficulty locating any supplier for talking glucose monitors. What can HCFA do to help blind consumers find participating suppliers?

13. Participating suppliers are listed in the Medicare Participating Physician/Supplier Directories, known as Medpards, which are compiled by the Medicare carriers and furnished to various senior citizen groups. Medicare beneficiaries can obtain a Medpad at no charge by contacting the Medicare carrier for their State. Information regarding how Medicare beneficiaries can obtain a Medpad for their State is provided on page 28 of the Medicare 1993 Handbook.

For the most part, the problems you mention in your inquiry deal with individuals who have experienced difficulty in obtaining accurate fee schedule amounts for E0607 and E0609. The fee information we have provided here is accurate and current.

Sincerely yours,
Kathleen A. Buto
Director
Bureau of Policy Development

• • •

Diabetics Division
National Federation of the Blind
Columbia, MO
August 11, 1993

Director, Bureau of Policy Development
Health Care Financing Administration
Dept. of Health and Human Services
Baltimore, MD

Dear Director Buto:

Thank you for your July 23, 1993 letter regarding Medicare policies and procedures for purchase of blood glucose monitors. The information you supplied helped clarify a number of points.

Unfortunately, some questions remain unanswered. Alaska and Hawaii are entirely absent from your chart #1, "Medicare fee schedules." Where I mentioned examples of official misinformation or departure from the national fee schedule guidelines, you request "documentation." Please understand that the specific examples of incorrect reimbursement and HCFA nonconformity with HCFA guidelines were revealed in telephone conversations between Diabetics Division researchers and the appropriate Medicare authorities. It is very difficult to "document" erroneous information supplied over the telephone. In the state of Texas, where specific documentation WAS available, the Texas Commission for the Blind is required by law to maintain client anonymity.

In the matter of "weighted averages" for E0609, you state that the current fee schedule amount (\$467.74) "exceeds the retail costs for one of the two available brands of blood glucose monitors with voice synthesizers." You do not address the fact that the national average cost for E0609, based on prices of both currently-available voice-assisted glucometers, is \$522.50, \$54.76 ABOVE the fee schedule ceiling. Why are blind diabetics still expected to lay out a far higher percentage of their own money than are the sighted for necessary medical equipment?

You state that the IR limit for E0607 is in the process of revision downward, reflecting decreasing prices for non-adaptive home blood glucose monitors. By the same standard, when can we expect an upward revision of E0609?

I fail to understand why an agency such as yours, mandated to be the "watchdog" over Medicare, shows such a marked reluctance to act. It would be a simple matter for you to test my assertions. The databases are yours; why depend solely upon client-supplied documentation?

The researchers for this project were all insulin-treated diabetics, members of The Diabetics Division of the National Federation of the Blind. On behalf of the Diabetics Division, I thank you in advance for your response.

Very truly yours,
Ed Bryant
President, Diabetics Division
National Federation of the Blind

cc: Donna Shalala, Secretary
Dept. of Health & Human Services

Diabetes control and complications trial

by Peter Nebergall
(Staff Reporter)



Peter Nebergall relates form and content of the recently-released federal DCCT study.

On June 9, 1993, the Federal Government released the results of the "Diabetes Control and Complications Trial" (DCCT), a large, long-term, fed-

erally funded study of the relationship between "tight," intensive diabetes control and the onset of diabetes complications. The study, conducted at 29 different centers across the U.S. and Canada, involved 1441 Type I diabetics, randomly assigned either to the intensive or conventional treatment group. The study's findings were significant.

The study found that patients who controlled their diabetes with an intensive regimen of blood-glucose regulation were 60 percent less likely to develop severe heart and blood vessel disease, 60 percent less likely to develop clinically-significant retinopathy, and 35 percent less likely to experience decreased kidney function than were patients employing traditional methods of diabetes control. Where traditional treatment for Type I diabetes has featured daily blood glucose tests and one or two insulin injections per day, intensive therapy features much more frequent testing, and up to four insulin injections per day.

If you or a friend would like to remember The Diabetics Division of the National Federation of the Blind in your will, you can do so by employing the following language:

"I give, devise, and bequeath unto The Diabetics Division of the National Federation of the Blind, 1800 Johnson Street, Baltimore, Maryland 21230, a District of Columbia nonprofit corporation, the sum of \$_____ (or _____ percent of my net estate) or the following stocks and bonds: _____ to be used for its worthy purposes on behalf of blind persons."

Findings of the DCCT study suggest that frequent testing and tight blood-glucose regulation can slow and perhaps prevent the onset of complications for the Type I diabetic. The impact such a regimen would have on the individual patient would depend in large part on the degree of complications already underway. While in no way proclaiming "tight control as a cure for diabetes," the study establishes statistical validation for a fact already intuitively grasped: that tight control of blood glucose does a better job of slowing the onset and progression of eye, kidney, nerve, and circulatory disease complications than does conventional insulin therapy.

Dr. James Gavin, President of the

American Diabetes Association, speaking on Pat Gallagher's national radio program, "Living with Diabetes," called the DCCT study "objective confirmation by real data gathered in the most precise and scientific way," and stated that now "providers will have to re-evaluate their approach and see if what they're doing is up to current standards of care."

CAUTION: Please note that intensive insulin therapy carries increased risk of hypoglycemic episodes, and would require increased vigilance. Any increase in the frequency of insulin injections raises the odds of insulin reactions. It is important to discuss this matter carefully with your physician.

Some health professionals tell blind diabetics it is unsafe to draw insulin

by Ed Bryant

The majority of health care professionals realize that blind diabetics can independently draw insulins and test blood glucose levels. But a few care providers persist in believing that people blind from diabetes cannot self-manage their disease. Their negative thinking is totally unfounded. Experience and statistics prove them wrong.

I am a blind diabetic who has independently drawn insulins and tested blood glucose levels for over twelve years. I am not exceptional. Like many people with severe vision loss from proliferative diabetic retinopathy, I self-manage my diabetes.

Some practitioners and nurses cling to society's old stereotypic attitudes, believing that the blind can't learn, can't care for themselves, and are incapable of being involved in the mainstream. No matter what they see, read, or hear, these health professionals are unwilling to train blind men or women to draw insulin, or to perform the other daily tasks that so many blind diabetics have been carrying out with complete success for years. I recognize that some people with diabetes, both blind and sighted, may not be able to independently self-manage due to numbness in the hands (neuropathy), impaired manual dexterity, severe arthritis, impaired mental function, etc.

Below are a few samples of communications directed to me from across the land. None of these blind diabetics have any of the conditions listed above; all are long term diabetics; most have used insulin for at least

fifteen years. I find their cases instructive.

- After losing sight from diabetes, a school teacher wanted to handle her own insulin needs, not wanting to bother others with what should have been a simple task. She went to her health care team to learn how to independently draw insulin, but was told that someone else would have to do it for her, simply because she was blind. (She was told it was unsafe.) Incidentally, this situation happened in a hospital setting.

- Another woman was told by a nurse that it would be unsafe to draw insulin as a blind person. The woman told the nurse that it was her understanding that blind diabetics could successfully draw insulin. The health care professional said she had special training in nursing and KNEW that it would be unsafe for a blind person to draw insulin. The woman then called me, seeking help, and I provided the name of an insulin measuring device that can easily and accurately be used by blind diabetics. The woman purchased one of these instruments and, as I advised her, took it to the nurse for examination. After a brief look, the nurse stated, "Well, it might work..."

• When one woman, who'd had diabetes for almost 40 years and was experiencing complications, started receiving *Voice of the Diabetic*, she discovered that education is as essential for practitioners as for diabetics. She explained to me that she was unhappy with her family physician because he had failed to answer her in-

quiries about diabetes — he didn't seem to have the time. Her insulin regimen was one daily injection; her doctor said there was absolutely no reason to consider multiple shots. When the woman changed doctors, the new physician looked her in the eye during her first visit and said, "I'm surprised you are still alive, having had diabetes as long as you have." She was so shocked by this insensitive statement that she forgot to ask about the possibility of drawing her own insulin. On telling me about her experiences with these two physicians, she said that all she wanted was to have a doctor who was willing to work with her to keep her diabetes in check. During my last communication with her, she reported that she still hadn't learned to draw up her own insulins because her physician treated her as though she were a child, because she was blind.

- A woman was losing sight from diabetes, but could still see to some extent with the aid of magnification. Because her vision was fluctuating, she consulted with her doctor to determine how to go about drawing insulin when she couldn't see the syringe clearly. The doctor suggested that she stop drawing her insulin and have someone draw it for her. She told the doctor she knew there were other legally blind diabetics who independently drew insulin and she was not about to have someone help her unless it was absolutely necessary. The doctor told her it would be too dangerous for her to handle her own insulin needs, and he could not be responsible if she did not listen to him. How unfortunate! The doctor was unwilling to listen and work with the patient. He did not realize that the blind, and those losing vision, can accurately draw up insulins.

- A 65-year-old woman who was born

blind was diagnosed as having diabetes. The physician prescribed insulin for best control. Being accustomed to using alternative techniques, the woman requested that someone instruct her how to draw up and administer insulin, as she saw no reason why she could not do it herself. The doctor replied that because of her blindness it would be unsafe for her to draw up insulin. He advised her to have her husband draw up the insulin and administer the shot. The woman told the doctor she was of sound mind, did not have shaky hands, and did not believe it would be unsafe for her to draw up insulin and give herself injections. All she needed was someone who was willing to show her how to "get the job done." The doctor "sympathized with her" but repeated that it was just too unsafe for a blind person to draw up her own insulin.

I tip my hat to those health care professionals who realize that blind diabetics are capable and can independently handle insulin needs. Although there will probably always be a few health professionals who will never believe the blind can do much of anything, the trend is toward teaching adaptive techniques.

Rarely will any publication covering diabetes issues carry anything negative about health care professionals. The *Voice of the Diabetic* enlightens readers about all aspects of diabetes including the need for education in the health care community. If you have thoughts about blind diabetics drawing insulin, I would appreciate hearing from you.

Note: See also the resource column, "What You Always Wanted To Know But Didn't Know Where To Ask," which lists adaptive equipment for blind diabetics.

Physician states frequent blood glucose monitoring by Type II diabetic is excessive

by Ed Bryant

The patient whose case is discussed below has requested anonymity. When his doctor told him it was unnecessary to keep close watch on his blood glucose levels, he felt misinformed by his health care team, and called the *Voice* for help.

All correspondence is reproduced here. Dr. Christie, as of press time, Sept. 27, has not answered my letter of June 25, even though he informed his patient (here relabeled Mr. Please Help) that he had received it.

Mr. Please Help is severely overweight, and has much trouble with food-related behaviors. Even so, and perhaps especially, he needs to monitor his blood glucose, and is clearly willing to do so. His unwillingness to modify his personal habits is insufficient reason to deny him the opportunity to monitor his blood glucose levels.

Why, one might ask, does he not merely change doctors? There are several reasons: First, he likes the doctor. Second, the financial details of his medical support arrangement encourage his remaining where he is.

It is well to remember that some health professionals still believe that blind diabetics (such as Mr. Help) are not capable of performing the necessary daily tasks of self-managing their diabetes. Clinging to this demonstrably incorrect assumption, they severely restrict the options of their patients. For whatever reason, ANY doctor who stands in the way of ANY blind diabetic learning independence, self-care, and that quality of life that comes from being master of one's own destiny, is simply wrong.

I am reminded of the story of the difference between ham and eggs. "The chicken is *involved*," the line goes, "but the pig is *committed*." The health care professional is involved, but it is well to remember that it is his patient, for better or worse, who is committed.

Diabetics Division
National Federation of the Blind
Columbia, MO
April 7, 1993

Michael Christie, M.D.
Family Medicine Center
Rochester, NY

Dear Dr. Christie:

I represent The Diabetics Division of the National Federation of the Blind, a national support and information network. I work with diabetics, especially those who are blind or losing vision, and with health professionals regarding diabetes issues.

Mr. Please Help, a blind patient of yours, has contacted me with matters needing clarification. I understand Mr. Help was told that he has very mild diabetes, and does not need oral medication or insulin.

Mr. Help tells me that about nine

months ago he had a hemoglobin A1C level of 9.6 and on March 8th of this year, it was 8.4. He wants to start regular testing of his blood glucose levels, keeping them under control, to minimize the chance of developing diabetes complications.

I am told that a member of your staff, nurse practitioner Carol Thiel, told Mr. Help that she did not see the necessity of glucose monitoring in his case. Describing his diabetes as "mild, not at a critical point," she would not endorse/recommend him to have a glucometer with voice enunciation. At that time a different nurse from the county health department was showing him how to do blood glucose monitoring at home. Mr. Help's health care program will not authorize such aid and instruction without documentation of need by the physician, so his glucose monitoring instruction has thus been terminated.

Mr. Help does not understand why a health professional would tell him glucose monitoring was not mandated in his case. I work with care providers nationally, and I too fail to understand why any nurse would tell a patient with hemoglobin A1C levels of 8.4 over a nine-month minimum that he had no need to monitor his blood glucose levels. Is this not the time for an "ounce of prevention?"

Mr. Help, an overweight Type II diabetic, has had the disease for perhaps 12 years or more. As his long-term high glucose levels may have already led to some organ damage, it is critical that his diabetes be kept under control.

Dr. Christie, I have three concerns:

1. Do you not encourage patients with high hemoglobin A1C to test their blood glucose levels? Figures this high surely warrant monitoring by the patient. Might a program of oral medication be called for, to reduce his glucose levels?
2. Do you train your staff in the importance of patients keeping their diabetes under control and checking glucose levels?
3. By far my greatest concern is for Mr. Help, whose high glucose levels need attention and appropriate health care.

I know you have a busy schedule; however, the above is important and I would appreciate receiving your response.

Very Truly Yours,
Ed Bryant
First Vice President
Diabetics Division
National Federation of the Blind

The Family Medicine Center
Highland Hospital Department of
Family Medicine

University of Rochester
Rochester, NY
April 16, 1993

Mr. Ed Bryant
Diabetics Division
National Federation of the Blind
Columbia, Missouri

Dear Mr. Bryant:

I recently received your letter regarding Mr. Please Help. Although he has been a patient at the Family Medicine Center for a while now, I have yet to meet him.

In reviewing his case with the Nurse Practitioner with whom I work, I find that Mr. Help apparently left a few details out during his conversations with you. While it is true that his hemoglobin A1C levels have been elevated they have been coming down, as you noted, with conservative approaches to treatment. As I am sure you are aware, using oral agents and/or insulin have potential complications and it is obviously better to avoid their use if alternatives are appropriate. In Mr. Help's case, his most recent fasting glucose checked in the office was approximately 100 and he was encouraged to continue efforts at weight loss to control his diabetes.

Finally, I would like to respond to your specific questions, which demonstrate your obvious concerns for Mr. Help and others struggling with various degrees of diabetes.

1. I do encourage monitoring of patients with high hemoglobin A1C levels, but at this point, I agree with the judgements of my associates here that frequency of monitoring that Mr. Help has apparently been requesting is excessive. Furthermore, I agree that the risks of medication at this point, probably outweigh the potential benefits.
2. The staff here is very aware of the importance of monitoring and controlling diabetes and have discussed these issues with Mr. Help.
3. I share your concern for Mr. Help and look forward to working with him on maintaining his health.

Sincerely,
Michael Christie, M.D.

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Diabetics Division
National Federation of the Blind
Columbia, MO
June 25, 1993

Michael Christie, M.D.
Family Medicine Center
Rochester, NY

Dear Dr. Christie:

This letter is in response to your April 16 letter to me regarding your patient, Mr. Please Help. I apologize

for the delay in getting back to you, but I was waiting for certain materials to be published.

I wholeheartedly agree with your emphasis on diet and exercise as important parts of diabetes self-care. They are vital. The 1993 publication from the Centers for Disease Control (CDC) titled *Prevention and Treatment of Complications of Diabetes: A Guide for Primary Care Practitioners* states that exercise is clearly indicated, and "may cause a modest drop in LDL cholesterol levels."

Proper diet and exercise help. What worries me is the reliance on such regimes as a panacea. There is no direct and absolute 1:1 correlation between exercise/diet regimes and the rate of progression of diabetes. Although the importance of good patient self-care cannot and should not be minimized, diabetic patients can take every precaution and still experience glycemic complications. The risks to the patient of assuming that self-care alone will halt the progression of the disease are great. It is necessary to know what the disease is doing, before irreversible complications announce their existence.

The CDC reports that persons with diabetes who develop neuropathy may have no detectable symptoms. The most common of the diabetic neuropathies, the CDC reports, is characterized by "insidious onset, symmetrical distribution, and progressive course." Current diabetes statistics (*Diabetes Surveillance*, U.S. Public Health Service) indicate that approximately twelve percent of diabetes patients show neuropathy at the time of diagnosis, but approximately sixty percent show neuropathy after 25 years of diabetes.

The just-published national study known as "The Diabetes Control and Complications Trial" reports that intensive treatments started early, before the onset of complications, even for Type II diabetes, can delay, minimize, or perhaps prevent future problems. In order to aggressively intervene, as suggested in this timely study, it is necessary to monitor a patient's blood glucose on a regular basis. Occasional monitoring carried out in a doctor's office is not sufficient to establish a pattern. Many diabetics are instructed to check their blood glucose twice a day or more.

Although Mr. Help is blind, that is no impediment to testing his own blood glucose and drawing his own insulin. Most blind diabetics are willing and able to carry out such activities, with the assistance of the adaptive devices available today. Your patient has indicated his willingness to learn and perform these activities.

Mr. Help relates that his Health Department nurse told him he didn't need a monitoring device; "he would be able to tell" if he were going into hyper- or hypoglycemia. Maybe. In the

"Ask the Doctor" column in the current issue of *Voice of the Diabetic* (copy enclosed), an insulin-dependent physician discusses the condition known as hypoglycemia unawareness, in which the normal "insulin reaction" symptoms of hypoglycemia are lost. For such people the first signs of hypoglycemia may range from altered vision to loss of consciousness. The spilling of ketones by an obese Type II diabetic, detectable by home blood sugar testing, if left untreated, can lead to serious diabetic ketoacidosis (DKA), unconsciousness, and the potential for permanent damage. Other diabetics (myself included) confirm the unreliability of relying solely on symptoms of physical discomfort to detect incipient hypo- or hyperglycemia. Regular monitoring is necessary to assure patient safety.

Once it has been established that a patient is diabetic, there are inherent risks in any policy of waiting for the disease to worsen, out of fear of the potential side effects of oral medications or insulin. Although at one time oral medications may have been considered more hazardous than insulin (but safer than nonintervention, surely?), recent studies do not continue to support such a conclusion. The University of Missouri—Columbia Medical School has participated in studies of newer oral agents. They have no problems with prescribing oral medications, and have seen no adverse side effects. They also studied the possible side effects of insulin, and reported that any possible risk has actually decreased since the development of human-recombinant DNA insulins.

An overweight diabetic such as Mr. Help is especially at risk of cardiovascular complications. The CDC reports that painless myocardial infarction is common among diabetic patients, and that angina or myocardial infarction may be present with atypical symptoms. Cardiovascular disease is the leading cause of diabetes morbidity and mortality. The annual risk for death from cardiovascular disease is two to three times greater for persons with diabetes than for persons without. As with other diabetes complications, cardiovascular degeneration may remain indetectable until it manifests to the point of severe to irreversible damage.

There is consensus among diabetes specialists that the only way to slow or arrest the progress of the disease is by frequent and regular monitoring of a patient's blood glucose, followed closely by the appropriate medications as indicated.

It is my intention to publish this letter and your reply, plus previous correspondence, in the next issue of *Voice of the Diabetic*, our nationally-distributed news magazine. I hope to hear from you soon.

Sincerely,
Ed Bryant
First Vice President
Diabetics Division
National Federation of the Blind
Editor, *Voice of the Diabetic*



Kenneth Jernigan is President Emeritus of the National Federation of the Blind. The Federation has more than 50,000 members.

(Editor's Note: Here is the text of Resolution 93-01, unanimously adopted by the more than 2000 delegates attending the 1993 annual convention of the National Federation of the Blind.)

WHEREAS, the word *blind* accurately and clearly describes the condition of being unable to see, as well as the condition of having such limited eyesight that alternative techniques are required to do efficiently the ordinary tasks of daily living that are performed visually by those having good eyesight; and

Euphemisms of blindness

by Kenneth Jernigan

WHEREAS, there is increasing pressure in certain circles to use a variety of euphemisms in referring to blindness or blind persons — euphemisms such as *hard of seeing*, *visually challenged*, *sightless*, *visually impaired*, *people with blindness*, *people who are blind*, and the like; and

WHEREAS, a differentiation must be made among these euphemisms: some (such as *hard of seeing*, *visually challenged*, and *people with blindness*) being totally unacceptable and deserving only ridicule because of their strained and ludicrous attempt to avoid such straightforward, respectable words as *blindness*, *blind*, *the blind*, *blind person*, or *blind persons*; others (such as *visually impaired*, and *visually limited*) being undesirable when used to avoid the word *blind*, and acceptable only to the extent that they are reasonably employed to distinguish between those having a certain amount of eyesight and those having none; still others (such as *sightless*) being awkward and serving no useful purpose; and still others (such as *people who are blind* or *persons who are blind*) being harmless and not objectionable when used in occasional and ordinary speech but being totally unacceptable and pernicious when used as a form of political correctness to imply that the word *person* must invariably precede the word *blind* to emphasize the fact that a blind person is first and foremost a person; and

WHEREAS, this euphemism con-

cerning people or persons who are blind — when used in its recent trendy, politically correct form — does the exact opposite of what it purports to do since it is overly defensive, implies shame instead of true equality, and portrays the blind as touchy and bigoted; and

WHEREAS, just as an intelligent person is willing to be so designated and does not insist upon being called a person who is intelligent and a group of bankers are happy to be called bankers and have no concern that they be referred to as persons who are in the banking business, so it is with the blind — the only difference being that some people (blind and sighted alike) continue to cling to the outmoded notion that blindness (along with everything associated with it) connotes inferiority and lack of status; now, therefore,

BE IT RESOLVED by the National Federation of the Blind in convention assembled in the city of Dallas, Texas, this 9th day of July, 1993, that the following statement of policy be adopted:

We believe that it is respectable to be blind, and although we have no particular pride in the fact of our blindness, neither do we have any shame in it. To the extent that euphemisms are used to convey any other concept or image, we deplore such use. We can make our own way in the world on equal terms with others, and we intend to do it.

O yes I can!

by Sandra Auburn

From the Editor: Sandra Auburn is the capable President of the Diabetes Division of the National Federation of the Blind of Georgia. An active Federationist, she leads her new division with enthusiasm and drive.

Although I was diagnosed as having diabetes about 12 years ago, it was only a year ago that I became insulin dependent. I never expected to become insulin dependent. The doctors didn't think I would be able to see the glucometer. Once I convinced them I could, the next question was: "How will you draw your insulin by yourself?"

I had thought about this. I told the doctors that I was a member of the National Federation of the Blind, and that I was sure there was someone in our Federation who could tell me how. Soon I heard about the Count-A-Dose insulin gauge and the NFB's Diabetes Division.

When I first started working with the people at the clinic, things were tough. The clinic staff had never seen

an insulin gauge. It only stands to reason they showed me the wrong way to use it. For almost a year, every time I drew insulin, I was drawing air bubbles into the syringe as well. Since I couldn't see the bubbles, I didn't know what was wrong. All I knew was that I was getting worse. It was Ed Bryant who talked to me, and explained how to do it right.

I am grateful that we have a Diabetes Division. After all, who knows the problems of the blind better than the blind themselves? The sharing of information through the division's support network is what helped me. Within a week's time, my blood glucose levels began to improve.

I was scared at first, when they told me I'd have to go on the needle. Now I do it every day, and don't give it a second thought. Yes, some days it is hard to get out of bed, but I remind myself that if I don't take that injection, I will be worse by nightfall.

I look forward to learning how to mix Humulin R and N insulins in the same syringe. I know now that it can



be done. Mr. Bryant has talked about it with me many times.

What upsets me the most is when doctors tell me that because I can't see, I can't take care of myself. When I butt heads with a wall like that it makes me want to work harder to prove to them that yes, it can be done. It simply has to be proven that we are indeed capable of doing things on our own.

I know the work of the National Federation of the Blind is vital, and I will do all I can to help. I thank God every night that we have a Diabetes Division. We should do all we can to support its work.

Adaptive diabetes education for visually impaired persons

From the Editor: In April of this year I participated in the Adaptive Diabetes Education for Visually Impaired Persons (ADEVIP) Consensus Development Conference. There were 16 participants from across the United States: certified diabetes educators, rehabilitation-for-the-blind personnel, and myself as lone consumer advocate. I was there representing The Diabetes Division of the National Federation of the Blind.

The consensus statement that emerged from this conference should be a positive step toward the goal of independent self-management by blind diabetics. Many health care professionals and rehabilitation counselors/teachers still believe that blind diabetics cannot independently draw insulins, test blood glucose levels, or perform other necessary tasks. Experience and documentation prove otherwise.

People with diabetes are correctly taught that education is essential for diabetes self-management. Education is just as essential for the health-care or rehabilitation professional, who needs to learn that blind diabetics, or those losing vision, can almost always self-manage the disease just as well as do their sighted peers.

Although the goals of the conference and the consensus statement are commendable, the endeavor included one unrealistic aim. There was a movement (reflected in the original language of the statement) to press for certification of all health-care and rehabilitation professionals. At this time I am aware of only one organization that offers certification to rehabilitation workers in the blindness field, and that organization is the Association for the Education and Rehabilitation of the Blind and Visually Impaired (AER). The inherent suggestion that workers in the blindness field who do not hold AER certification are less competent is unsupportable.

In the consensus statement, published below, the authors claim "support of the blindness rehabilitation community" for their viewpoints. There is less consensus than their statement suggests. The National Federation of the Blind (NFB), the largest and oldest organization of blind people in existence, sponsors several rehabilitation centers for the blind, and staff certification is not required. The success rate for people graduating from these centers is very high. Staff members are well trained, highly motivated, and believe in the abilities of blind clients. For information or assistance concerning any problem with blindness, or the location of appropriate rehabilitation services, contact the National Federation of the Blind, 1800 Johnson Street, Baltimore, MD, 21230; telephone: (410) 659-9314.

The NFB's Job Opportunities for the Blind (JOB) program (co-sponsored by the U.S. Dept. of Labor) is a no-charge job-referral service, open to any legally-blind U.S. resident. The JOB program also advises prospective em-

*ployers of the blind, and counsels blind workers, and those losing vision, on job retention. JOB publishes a bi-monthly bulletin of job listings, tips, and employment information, called the **JOB Recorded Bulletin**. For information, or to receive a sample packet, call 1 (800) 638-7518.*

What kind of training should the rehabilitation professional receive? Rather than concentrating on some imposed-from-above notion of "certification", far better to focus on the development of the physical skills necessary to function without sight, and on the empowerment of individual blind clients. Too few rehabilitation teachers actually believe that the blind can compete on equal terms with the sighted. A rehabilitation professional must understand and accept the abilities of blind clients, otherwise he or she will unnecessarily limit their options. The facilitation, reinforcement, and improvement of the options open to blind diabetics must be the paramount goal of rehabilitation.

Most health-care and rehabilitation for the blind workers do their work very well. If the following consensus statement is read as a call for further education of professionals, interests of blind diabetics and those losing vision will be served.

The "Guidelines for Practice" statement, as presented here, has been edited for publication. Lengthy, detailed explanations have been pared down, and phrasing has been modified for clarity. ADEVIP is a new approach, and as a "call to action," this statement could not have come at a better time.

GUIDELINES FOR PRACTICE OF ADAPTIVE DIABETES EDUCATION FOR VISUALLY IMPAIRED PERSONS (ADEVIP)

History of ADEVIP and the consensus development process

Tools and techniques for diabetes self-care have dramatically improved in the last decade, most notably adaptive equipment for the visually impaired. With modern adaptive equipment, it is now possible for visually impaired people to take full charge of whatever level of diabetes control they and their doctors choose. At the same time, a mandate to provide equal access to modern health care, including adaptive health care for people with disabilities, is implicit within the Americans with Disabilities Act. Yet most diabetes educators, rehabilitation teachers, and third party payers still lack the knowledge necessary to make independent diabetes self-care a reality for all visually impaired persons.

The guidelines in this text grew out of the work of the Visually Impaired Persons Specialty Practice Group (VIP-SPG) of the American Association of Diabetes Educators (AADE), the Association for the Education and Rehabilitation of the Blind and Visually Impaired (AER), with the support of

the blindness rehabilitation community. Before this point, no guidelines for ADEVIP had been available.

The VIP-SPG first met at the 1988 AADE Annual Meeting, where they began working on guidelines to be implemented in 1990. The brief time allotted to their meetings was scarcely sufficient to begin. Funding was sought for a consensus conference to develop guidelines for the practice of ADEVIP as a specialty.

In 1992 the American Association of Diabetes Educators and the Diabetes Research and Education Foundation granted the necessary funding for a consensus development meeting of the Task Force on ADEVIP. Participants in the Task Force were selected from a pool of applicants, based on: substantial experience working with visually impaired diabetics, diversity of professions, and the diversity of geographical areas represented. The Task Force held its consensus development meeting on the weekend of April 23-25, 1993, at the Cleveland Sight Center in Cleveland, Ohio. In the extensive preparation process and in the meeting itself, many ideas were generated. This document is a compilation of those ideas.

Definitions, values and assumptions

Adaptive Diabetes Education for Visually Impaired Persons (ADEVIP) is defined as the specialized diabetes education a visually impaired person needs, in addition to basic diabetes education, in order to perform diabetes self-care tasks as independently as possible, and to recognize and plan for any needed assistance. ADEVIP draws from the expertise of two professional disciplines: diabetes education, and rehabilitation teaching for blind and visually impaired people.

Visual Impairment, for the purpose of these guidelines, is defined as any vision loss sufficient to cause difficulty in performing diabetes self-care tasks accurately and consistently, when using the standard, visually oriented, tools and techniques.

The Task Force on ADEVIP recognizes that certain assumptions are implicit in these Guidelines. These assumptions are:

1. We value self-care.
2. We value self-care education as an integral part of health care for all people, including those who live with a complicating disease or disability.
3. We value empowerment, the process by which people gain mastery over their own affairs.
4. People who live with visual impairment and blindness are capable of competent self-care.
5. We expect that all professionals who teach ADEVIP will adhere to all the accepted published guidelines pertinent to their professional practices.

Professional education background and role delineation

Competent teaching of ADEVIP requires at least a basic familiarity with both diabetes education and visual impairment rehabilitation. There are several ways to achieve such a competency:

- I. DIABETES EDUCATOR: A professional education with appropriate licensing in a health profession (health education, nursing, or medicine), preferably with specialization and certification in diabetes education, and
- a thorough familiarity with current visual impairment rehabilitation, and
- a thorough familiarity with ADEVIP tools and techniques, including hands-on experience.

- II. REHABILITATION TEACHER: professional education, or its equivalent, in visual impairment rehabilitation, and
- a thorough familiarity with diabetes education, and
- a thorough familiarity with ADEVIP tools and techniques, including hands-on experience.

Role Delineation

The preferred approach to teaching ADEVIP is through use of a multidisciplinary team, which would include both a diabetes educator and a rehabilitation teacher.

- I. Diabetes Educator: the task of this individual would be to help empower clients to self-manage their diabetes.
- II. Rehabilitation teacher: this individual would concentrate on communicating to the client the necessary low-vision and non-visual techniques for independent living.

If possible, it is preferred that the diabetes educator teach ADEVIP; the rehabilitation teacher should serve in the role of consultant on non-visual techniques. However, in medically underserved areas, a rehabilitation teacher may, of necessity, teach ADEVIP without a readily available diabetes educator. In such a situation, the rehabilitation teacher has a responsibility to carefully observe the following boundaries of responsible practice:

1. The rehabilitation teacher must have more than a minimal introduction to modern diabetes care.
2. Before beginning to teach ADEVIP, the rehabilitation teacher should contact the client's primary health care professional, to assure that the client has had basic instruction in diabetes self-care.
3. To avoid liability, the rehabilitation teacher must avoid practices beyond the professional expertise of rehabilitation. Questions relating to specifics of medication, nutrition, or exercise should be referred to a health professional. The rehabilitation teacher should teach adaptations only.

4. Once the client has learned the ADEVIP technique, before he or she starts relying on it for self-care, a return demonstration should be arranged with the client's health care professional.

Process and content of ADEVIP

As noted above, it is expected that all professionals who teach ADEVIP will adhere to process and content guidelines that apply to their profession. The guidelines presented here apply specifically to ADEVIP, and do not replace or eliminate the need for complete basic diabetes education and visual impairment rehabilitation.

Process of ADEVIP

1. ADEVIP instruction must be individualized.
2. Equipment and techniques must be carefully matched with the individual client's needs and abilities.
3. Choices should be offered whenever choices are available.
4. The professional who teaches ADEVIP must ensure that the client can perform the non-visual techniques accurately and safely before relying on them for self-care.

Content of ADEVIP

I. Assessment

An individualized ADEVIP assessment should include information from the client in the following areas:

1. Functional visual ability for diabetes self-care tasks.
2. A compilation of the diabetes self-care tasks needed, and the degree of flexibility needed to perform

them.

3. Other impairments and disabilities

II. Physical Self-Care Needs

The content of ADEVIP should include, but not be limited to, the following topics:

1. Insulin measurement and administration
2. Self-monitoring of blood glucose
3. Sharps disposal
4. Other medication identification and administration
5. Foot care
6. The planning of safe and appropriate exercise
7. Needs in nutritional area: nutritional reference material (exchange lists, recipes etc.) in an accessible form; food preparation, food measurement, food shopping skills
8. Other health related adaptive equipment: talking scale, talking blood pressure meter, talking thermometer, tactile use of insulin pump, tactile operation of peritoneal dialysis equipment.
9. Record keeping
10. Providing diabetes education resources (books, magazines, and videos) in accessible format

III. Emotional and Social Needs

A. The professional who provides ADEVIP will probably not have responsibility for extensive care in such areas, but should be aware of common problems, and be prepared to refer the client to appropriate professionals if more extensive care is needed.

1. Dealing with loss and grief: self-

image, job, family role, sensory experience, driving

2. Dealing with feelings about dependence, independence, and interdependence

3. Dealing with emotional fluctuations — the "yo-yo" effect

4. Emotional difficulties: depression, denial, guilt, feelings of being overwhelmed, feeling helpless and powerless

5. Social difficulties: negative impact of diabetes and visual impairment on family life, work, school, social activities (such as church, clubs, etc.); special needs of those who live alone

B. In addition to referrals within the medical and blindness rehabilitation systems, referrals to other community resources for information and services may also be helpful:

1. Contact with positive role models (national advocacy groups, peer counseling, and support groups)
2. Assertiveness training, with special focus on health care
3. Legal rights (especially regarding Americans with Disabilities Act) and entitlements
4. Local special services (housing, transportation, services for the elderly, etc.)
5. Religious or spiritual counselling
6. Stress management
7. Vocational services

IV. Follow-up

Because needs, abilities and human memory often change over time, follow-up at regular intervals to re-check adaptive self-care techniques is necessary

AADE Convention

On August 18 through 22, 1993, the American Association of Diabetes Educators (AADE) held its national convention in Atlanta, Georgia. The Diabetes Division of the National Federation of the Blind secured booth space in the exhibit hall, and handed out thousands of pieces of literature concerning diabetes and blindness. Most AADE members in attendance were Certified Diabetes Educators.

The booth workers were: Diabetes Division President Ed Bryant; National Federation of the Blind of Georgia Diabetes Division board members Sandra Ausburn, President; Max Parker, Treasurer; and Kaye Zimpher, Secretary.

President Bryant reports that countless conventioners stopped at the booth to tell him they received the *Voice*, and they thought it was very good. They found the publication most helpful in their work with patients who had diabetes. President Bryant says he was impressed with the AADE convention, where he found conventioners very interested in learning adaptive techniques to show blind diabetics how to independently draw insulins, test blood glucose, etc.

"It is clearly evident that many health professionals want to learn adaptive techniques of self-management for the blind. I believe that the AADE is making efforts to educate its membership about the abilities of blind diabetics," he states.

not realize it at the time.

Eye strain was a constant problem for me in school. How wonderful and practical it would have been to make an easy transition from print work to Braille when I used my eyes too much.

My father tutored me every night in math for years. My mother read to me so much than by my senior year in high school, she had damaged her vocal cords. I always loved school despite the hard work. I was feature editor for both my junior and senior high newspapers.

I earned a Bachelor of Arts degree from that same MacMurray College where my mother had despaired for my future, 19 years earlier.

College took me four and a half year and four straight summers to complete. I am now convinced that if I had had good Braille skills, I might have been able to handle four courses a semester like everyone else instead of taking only three. I had a totally blind friend a year behind me in college who did take full course loads each semester and used Braille.

Students, join and become active in the NFB. It is the greatest gift you can ever give yourself. Take the initiative to learn Braille and cane travel. This may seem a tall order, but believe me, it is an essential one. You will find all the positive role models that you always needed in the NFB. You will learn that it is respectable to be blind.

Partially sighted, really blind

by Catherine Horn Randall



Catherine Horn Randall shares her experiences as a blind person. "It is respectable to be blind."

From the Editor: Catherine Horn Randall serves as chairperson of the Committee on the Senior Blind, of the National Federation of the Blind. An active federationist, she responds to seniors' concerns about blindness.

Mrs. Randall can be contacted at: #11 Pitner Place, Jacksonville, IL 62650; telephone: (217) 243-3529.

One rainy afternoon, a young mother stood across the street from Main Hall on the MacMurray College campus in Jacksonville, Illinois, watching the busy, laughing college co-eds come and go. She cried for her four-year-old daughter who might not have the opportunity to go to college or lead a full life because she only had partial sight in her right eye. She was afraid and wondered about Cathy's future, and all she knew to do was to have Cathy evaluated by the professional staff of The Illinois Braille and Sight Saving School in Jacksonville.

The professionals told her that Cathy had so much sight that she wouldn't need to bother with Braille. The bewildered young parents were grateful to the experts for their advice: who else could they turn to? The school didn't tell them that the National Federation of the Blind even existed. Cathy's parents took her home determined to enroll her in the sight saving program in Quincy, Illinois.

From this point on, I shall tell my own story. As I look back at the enormous implications to my life and to my education from being denied the opportunity to learn Braille as a child, I am as angry and frustrated now as my mother was afraid for my future in 1951.

I happened to be an only child, and I like to think that I was constructively spoiled by my parents. My parents could not have been more supportive of me. If they had received common-sense guidance, I know I would have learned Braille. Whatever I needed to help with my education my parents enthusiastically provided. If only we had known that what we needed most was the National Federation of the Blind, braille, and cane travel skills. Unfortunately for me, we used the term "partially sighted" while I was growing up. I wasn't really blind because I had some sight, so I didn't think of myself as blind until I began losing my remaining sight in my late 20's.

I was a blind child and a blind college student who was trying to get along without either of the most important skills of blindness, namely braille and cane travel.

I took typing lessons when I was 10, and again in both junior and senior high. Typing, I feel, is another essential skill for blind and legally blind students.

A partially blind student who reads print and takes notes with Flair pens or markers and uses tapes is still greatly handicapped if he or she does not know Braille.

I didn't have much confidence in myself in high school or college, and I think not having the skills of blindness was part of the reason, although I did

Spotting your doctor's medical mistakes

Recognizing common errors

by Gary Legwold

Who are you to be telling your doctor, "I think you've made a mistake"? Believe it or not, you don't need a degree from Harvard Medical School to spot many of the most common errors that doctors make. In fact, in this day of hurry-up medicine and cost-cutting programs, patients must take more responsibility than ever for the quality of their medical care.

What kind of mistakes? No one expects you to spot the sort of technical errors that lead to malpractice suits — giving you the wrong drug during a heart attack, for instance. You also probably won't spot "mistakes" that arise because of honest differences among doctors.

"Medicine is an imprecise science," says Tom Reardon, M.D., a trustee of

Yes, some doctors still give this demeaning reply. It's a sign that your doctor refuses to link stress or emotional turmoil to such physical ailments as ulcers, headaches, backaches, and bowel irregularities.

This kind of response may also indicate that the doctor cannot spot depression. Signs of depression (sleeplessness, feeling "blue," fatigue, low self-esteem, eating too much or too little) may be pooh-poohed or misdiagnosed by doctors. Sociologist Marilyn Potts, Ph.D., at California State University, Long Beach, found 49 percent of a group of depressed women were not diagnosed as such by doctors; 65 percent of a group of depressed men were misdiagnosed.

If your doctor has an all-in-your-head attitude, switch doctors. Or at least ask that he or she refer you to a professional in mental health. "A good doctor will talk *with* patients, not down to them," says Michael Fleming, M.D., a Shreveport, Louisiana, family practitioner. "There are no stupid questions. For the money doctors get, they should be able to hear you out and help."

2. Lousy handwriting and sloppy records.

Some hurried doctors claim bad handwriting is no big deal. Pharmacists can always call the doctor about illegible prescriptions, they argue.

"In theory that's how it works, but not always in practice," says Michael A. Donio of the People's Medical Society in Allentown, Pennsylvania. True, pharmacists get to know their customers' needs, but the pharmacist, who may also be hurried, "may not know you from Adam," Donio says. He adds that some patients hop from pharmacist to pharmacist or have two or three physicians prescribing medications. With more professionals involved, the chances of error increase — even when the doctor's handwriting is good.

Bad handwriting also causes poor record keeping. Sometimes doctors don't read the whole patient file, especially when they can't read their own writing. With no easy-to-read log of medications, the potential exists that "new medications will conflict with the old," says Larry Dickey, M.D., in the U.S. Department of Health & Human Services. "You could have a string of medications that add up to something bad for the patient."

Dickey's advice is to keep your own medication records and cross-check them with your doctor's. Also, make sure you can read prescriptions and understand the drug and dosage.

3. Failing to keep current.

Beyond reading journals and meeting continuing education requirements, family doctors, for example,



must prove they are current by being recertified every six years. Even with this constant study, doctors cannot possibly keep up with research in all specialties. But they should show a respect for new developments and a willingness to refer to specialists.

For example, good doctors outside of the field of rheumatology won't know about all 106 forms of arthritis. But they can do a thorough history and exam before referring to specialists. "They shouldn't say, 'Oh, it's just arthritis. You'll have to live with it,'" says Cody Wasner, M.D., a Eugene, Oregon, rheumatologist.

The only way patients know if doctors are current is by educating themselves using materials from such groups as the Arthritis Foundation, the American Cancer Society, and the American Heart Association.

4. Starting lengthy treatment after one test.

Even in this day of cost containment, several tests are usually needed for a diagnosis. If your blood pressure is high once, that doesn't necessarily mean you need medication. Readings vary as much as 20 milligrams Hg depending on whether you stand, sit, or lie down. Stress, time of day, and caffeine are also factors. Just having a doctor present can raise your blood pressure — so-called white-coat hypertension. Blood sugar levels vary, too, and may be high one hour after eating, then normal four hours later.

The solution is to have several readings, preferably over a period of weeks. If your doctor doesn't order

them, ask for them. Doctors should also ask about other symptoms such as headaches and dizziness.

There are exceptions to the several-readings rule. If one blood pressure or blood sugar reading is off the charts, the patient is at risk. In these cases, says Stuart Hanson, M.D., president of the Minnesota Medical Association, you have no choice but to medicate first and recheck later.

5. Prescribing antibiotics "just to be safe."

Offering antibiotics can be sloppy — or good — medicine. It's sloppy when your cold is caused by a virus, which antibiotics won't kill. Therefore, your money is wasted.

On the other hand, more than 50 percent of lung infections do respond to antibiotic treatment. Doctors can do expensive, time-consuming tests to find the bug, or they can go with the odds and offer antibiotics. It's cases like these that rely on the judgment of the doctor, explains Hanson.

Another factor in overprescribing antibiotics: "Patients may get huffy because their doctor won't give them anything," says Donio. Arthur Levin, of the Center for Medical Consumers in New York City, adds that doctors may be "quick with the pad when patients demand it. Some won't refuse patients because they do not want to lose them."

Ask why your doctor is prescribing antibiotics. Perhaps get a second opinion. But if the doctor doesn't prescribe — and explains why — don't get huffy. Sometimes the best medicine is none at all.



the American Medical Association. He points to a study showing that one medical problem was treated four different ways in four countries.

Fortunately, the most common mistakes doctors make are less than catastrophic and far easier to spot before they do harm.

We polled medical experts from around the country to develop a list of the mistakes patients can catch. We also garnered advice on how to handle these situations when they arise.

It's also important to know that doctors today — the good ones, at least — welcome patient input. This is a new age of medicine in which doctors form partnerships with patients and encourage them to learn enough about medicine and their bodies to spot some common medical mistakes.

Of course, doctors sometimes don't like to be told they are making mistakes. Still, you must persist; your health, after all, is at stake. Here are mistakes you can spot and do something about.

1. Telling you your problems are "all in your head."

6. Offering no alternatives to surgery.

Sometimes surgery is the only solution, but in many cases other treatments are less invasive. Diverticulitis, a bowel inflammation, can be fixed by colon surgery, says Reardon. But medication and a change in diet also can work. Depending on the circumstances, it's your choice, but only if your doctor offers you the option.

"In many cases, differences of opinion about treatment exist among physicians," says Levin. "Doctors should tell that to patients."

A second opinion is critical with surgery. Levin says beware of doctors who refer you to buddies in the same specialty who may rubber-stamp your doctor's advice. You might try someone in a related specialty. For example, for back surgery you might talk to a specialist in rehabilitative medicine.

7. Not promoting prevention.

Times are changing because of rising health care costs, but preventive medicine is not the strong suit of many doctors. "A doctor's training is mostly in hospitals with highly inten-

sive cases," notes Reardon.

The irony is, many of these cases could have been avoided with preventive medicine. For example, checking blood pressure, blood sugar, and cholesterol; tracking immunizations; encouraging breast self-exams, mammograms, and pap smears for women and prostate exams for men; and urging physical activity, nutritional changes, and no smoking.

"A lot of physicians don't ever ask patients what they eat, or if they do, it is related just to diabetes," says Sheah Raback, M.S., spokesperson for the American Dietetic Association and faculty member at the University of Miami School of Medicine. Too bad, she says, "because heart disease and cancer are our number one and two killers, and food has a role in preventing both of them."

Patients also play a role in prevention. Keep pressuring your doctors about it, but also heed their advice. Good medicine is a partnership.

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Ask the Doctors



NOTE: If you have any questions for "Ask the Doctors," please send them to the *Voice* editorial office.

Bart Martyak, M.D. is an ophthalmologist associated with Day, Patterson and Whitten, M.D., P.C. in Washington, D.C.

What is diabetic retinopathy?

The retina is a thin layer of nerve tissue in the back of the eye from which focused light or images are carried to the brain via the optic nerve. The macula is a highly specialized part of the retina that is most responsible for central vision. The normal retina has competent blood vessels that do not leak fluid; these blood vessels supply nutrients to the cells in the retina. It is the deterioration of the retinal blood vessels that causes the complications that can lead to decreased vision.

There are several forms of diabetic retinopathy. **Background retinopathy**, the least severe form of diabetic retinopathy, is characterized by changes in the retinal blood vessels. Constriction and dilation of these vessels can cause obstruction of normal blood flow, hemorrhage, and leakage, which cause the formation of protein (lipoprotein) deposits called *exudates*. The small red dots seen by the ophthalmologist are microaneurysms, or saccular outpouchings of the vessels. This is where the leakage occurs. Later, these vessels undergo constriction and decreased blood flow, there-

fore reducing nutrient delivery to the retinal cells. In an attempt to once again deliver more nutrients, fragile new blood vessel formation occurs (*neovascularization*). This more advanced stage of diabetic retinopathy is the most threatening form of the disease, and is called **proliferative retinopathy**. These new blood vessels can hemorrhage and form scar tissue, which causes traction on the retina. If the traction is severe enough, retinal detachment may result, causing severe vision loss and the need for surgical treatment.

Another major vision-threatening form of diabetic retinopathy is **macular edema**. Macular edema can occur with either background or proliferative retinopathy. This edema is leakage of fluid into the central visual area — the part of the retina responsible for the sharp, clear vision used in reading and driving. When critical areas of the macula become swollen with excess fluid, vision may be so badly blurred that these activities become difficult or impossible.

Who gets diabetic retinopathy?

Epidemiologic studies suggest that 700,000 Americans already have proliferative diabetic retinopathy and that 65,000 new cases occur annually. Approximately 500,000 Americans suffer from macular edema with 75,000 new cases occurring annually. The annual estimated incidence of blindness from diabetic retinopathy is over 8,000 new

Neuropathy need not limit travel

(Continued from page 1)

made walking down the street probably had the neighbors talking for days.

During our walk, I told him of my problems with neuropathy, wondering if it would interfere with obtaining a dog. He proceeded to tell me about a former student who had a type of epilepsy that caused him to go into a seizure if he tripped over obstacles in the pavement. He was matched with a dog, and after some tough going, they graduated as an effective working team. The instructor saw no reason why I too could not become a successful guide dog user.

My four weeks at The Seeing Eye School were arduous. It seemed we were on the go every moment. Almost every time we worked our dogs, I fell. By the end of training, my knees were an absolute mess. But I went home with a beautiful German Shepherd female named Lark. Lark and I were together for 7 1/2 years. I traveled more during this period than when I could see and drive.

Now I have another female shep-

herd, a spunky thing by the name of Jingles. Where Lark was aloof, a one-person dog, "Jingles" is a dog of a different color. With her at my side, I have traveled to many more new places.

Canes have their place, and sometimes I find it necessary to use one. The same basic techniques of using a cane apply in handling a dog, the same orientation and mobility skills. For me, though, there is nothing like the feeling of moving quickly and effortlessly through crowds, downtown traffic, or along quiet neighborhood streets, my dog guiding me efficiently around obstacles, under overhanging limbs and signs, or carefully past cracks in the pavement. Plus I get the side benefit of all that exercise.

I enjoy the companionship my dog offers, even though much is required in caring for her. To me, the extra effort is worth it, because the world opened up to me the very first time I picked up the harness handle and said, "Lark, forward."

cases in the United States alone.

Many studies have shown that the best predictor of diabetic retinopathy is duration of the disease. Diabetic retinopathy affects 60% of those who have had diabetes mellitus for more than 15 years, and 70% of all persons with diabetes over their lifetimes. Another determinant of the prevalence of diabetic retinopathy is the age of the patient. Both the age at the time of diagnosis as well as the chronological age are important. Prepubescent children rarely develop retinopathy. Background retinopathy and macular edema appear sooner in people in whom the diagnosis of diabetes is made after the age of 40 years than in younger people. Therefore early detection and timely laser or surgical treatment is critical in maintaining good vision.

Timely laser photocoagulation of the retina can reduce the risk of visual loss from proliferative diabetic retinopathy by at least 50%; moderate visual loss from diabetic macular edema also can be reduced by 50%. Some individuals with vision loss from diabetic retinopathy can have restoration of useful vision with vitrectomy surgery (removal of hemorrhage and scar tissue). Thus, visual loss from diabetic retinopathy can be prevented, delayed, or treated with appropriate and timely interventions.

Ronald James, M.D. is an endocrinologist diabetologist who directs the Midwest Diabetes Treatment and Education Center in Columbia, Mo. Dr. James is also an insulin-dependent diabetic.

I am visually impaired due to diabetic proliferative retinopathy. I use a long white cane to travel safely

and have applied for and been accepted for a Guide Dog. In preparation for Guide Dog school I have been walking regularly (five times a week) at a fast pace (three miles an hour). What is the best time of day to perform this walking exercise? I have been doing this walking regime in the early morning hours. However, my work schedule is changing and I must now exercise after returning home from work (between 6:30 and 8:00 p.m.). I am prone to insulin reactions, as I cannot feel them coming on until my blood sugar readings are down in the high 30's and low 40's.

It is generally felt that the best time to exercise may be after a meal. Assuming you are having dinner before 6:30 p.m., it appears you are doing this. Since you are exercising five times a week (not every day) and tend to have insulin reactions, you may need to take extra food in the form of starch and/or protein before walking. If you are taking regular insulin before dinner, you may wish to decrease it. Because you have difficulty recognizing insulin reactions until your blood sugar is in the 30's or low 40's, you should do a blood sugar before starting to walk. If feasible with your impaired vision (perhaps a spouse or someone else to help if needed could walk with you), you may even carry a meter with you to do one every 30 minutes or so as needed during the walk. Of course, carry food and some form of sugar to take, in case your blood sugar is low or becomes low.

(Editor's Note: There are several blood glucose monitoring systems that have voice enunciation so the blind can independently test their blood glucose levels.)

The National Federation of the Blind

The National Federation of the Blind is the largest organization of the blind in the United States. Interested sighted persons also join. Founded in 1940, the Federation has grown to include more than ten percent of the nation's blind (over 50,000 members).

The Federation is organized in every state and has local chapters in almost every community of any size in the nation. Where there is no local chapter, there are members at large. Each year the National Convention of the Federation is attended by approximately 2,500 blind persons, which makes it the largest gathering of blind people in the history of the world and one which is growing each year.

The ultimate purpose of the National Federation of the Blind is the complete integration of the blind into society on a basis of equality. This objective involves the removal of legal, economic, and social discriminations; the education of the public to new concepts concerning blindness; and the achievement by all blind people of the right to exercise to the fullest their individual talents and capacities. It means the right of the blind to work along with their sighted neighbors in the professions, common callings, skilled trades, and regular occupations.

There are numerous governmental agencies and private charitable organizations and foundations providing services for blind people, but only the blind themselves (acting through their own organization) are able to speak for the blind. This is a basic concept of democracy.

The Newly Blind

Blindness knows no discrimination. Any child can be born blind. Any individual can become blind in childhood or later life. It is in the best interest of every individual to understand blindness and how to cope with its problems.

The newly blinded person faces a difficult adjustment. Studies have shown that only cancer is feared more than blindness. However, blindness does not need to be the tragedy that it is generally thought to be. One of the best medicines is to meet other blind people and learn of their jobs and the techniques they use in doing things without sight. Membership in the NFB provides this common meeting ground and, even more important, a sense of participation and restoration of confidence. Members in the NFB contact newly blinded persons to help them with problems of adjustment and orientation. Local chapters ordinarily hold monthly meetings, and state organizations usually meet annually. The National Convention is held each summer in a major American city and is the ultimate authority of the Federation, which establishes all policy.

The newly blinded person must also know where and how to get the training and services he or she needs.

The National Federation of the Blind can work with the person to find and provide information on available services from governmental and private agencies, as well as facts about laws and regulations concerning the blind.

More and more governmental agencies and private foundations are becoming responsive to the views and needs of the blind and are learning new concepts and attitudes about blindness. The future looks bright. There is an overwhelming feeling of goodwill and a wish to help on the part of the general public. Most important of all, the blind are moving forward to speak for themselves and take a hand in the management of their own affairs through their organization, the National Federation of the Blind.

Programs and Services

Public Education — By means of speeches, pamphlets, and radio and TV appearances, members of the NFB strive to educate the general public to the fact that the blind are normal individuals who can compete on the basis of equality with their sighted peers.

The Braille Monitor is a monthly publication of the NFB devoted to issues, news, and events that have special significance to the blind. It is published in Braille, in print, on record, and on cassette and is available without cost to the blind and sighted alike upon request to the National Office of the NFB.

Job Opportunities for the Blind — Blind persons seeking employment may use regular public and private employment agencies. However, because of widespread misconceptions about the abilities of the blind, special employment services may be more helpful. Blind people today work as lawyers, psychologists, machinists, farmers, and hairdressers; but the best estimates indicate that 70 percent of those who are able to work still do not have jobs or work only a few days a month in sheltered workshops. Many thoroughly capable blind persons have never had a job.

To respond to this critically high unemployment rate, the National Federation of the Blind, in cooperation with the United States Department of Labor, developed a program called **Job Opportunities for the Blind** — JOB. JOB helps qualified blind people who are looking for work find employers with job openings. JOB also helps employers, seeking competent workers and compliance with affirmative action requirements for hiring the handicapped, find truly qualified employees. JOB conducts educational seminars about blindness for employers and career-planning seminars for unemployed blind people.

Protection of Rights — There are barriers to full participation in society by the blind. The National Federation of the Blind stands ready to help blind people overcome these barriers when

collective action is necessary to invoke protection of applicable state and federal laws in such areas as employment, education, housing, insurance, public transportation, and public facilities.

Social Security Benefits

Legally blind persons who have paid into the Social Security system may be eligible for Social Security Disability Insurance (SSDI) under the special rules that apply to the blind.

Legally blind senior citizens considering early retirement should first learn if they might qualify for more benefits under SSDI. Blind persons who have little or no regular income or savings may qualify for monthly payments under the Supplemental Security Income (SSI) program. Again, there are special rules which apply only to the blind. Local Social Security offices have information and applications. The National Federation of the Blind can help with problems in understanding the regulations, incorrect denial of benefits, or related problems.

Rehabilitation — Every state has a public rehabilitation or vocational rehabilitation agency which provides training, counseling, and employment placement services to the blind. Sometimes the service is provided directly, and sometimes it is contracted out to private rehabilitation facilities. Some funds through the rehabilitation agency are usually available to students for college education or other post-secondary training. The NFB's National Office can provide information about where to apply for services in your area.

Library Services — Every state has free library services for those who, because of a physical or visual defect, cannot read ordinary print books. Books and magazines are available (on loan or free of charge) in Braille, in large print, and on cassette and record. Special cassette machines and record players to use in listening to the taped or recorded reading material are also loaned without cost to blind library users. For details about where and how to apply for services in your area, you may contact the NFB or your local library.

Free Reading Matter Mail Privilege — Recorded, Braille, and large print reading matter (including library books and magazines) may be mailed to and from blind persons free of charge if

"Free Matter for the Blind" is written or stamped on the envelope or package. Braille watches, white canes, or other special appliances for the blind are included in this privilege. The NFB will be happy to answer questions about the

Free Reading Matter Mail Privilege.

Education of Blind Children — The passage of Public Law 94-142, the Education of All Handicapped Children Act, established certain rights and protections for blind children and their parents. Blind

children are now entitled to a free public education in the "least restrictive environment," and parents have the right to help plan their child's educational program. Contact the NFB for more information about the education of blind children, parent organizations, newsletters, etc. Also, the National Federation of the Blind publishes a magazine for parents of blind children. This publication provides information and insights into all aspects of raising blind children from infancy to adulthood. A free subscription is available to parents and other interested persons by writing to *Future Reflections* at the NFB National Office.

Scholarships — Blind students can take advantage of the same scholarship programs that are available to sighted students and should be encouraged to do so. However, there are also scholarships that are only available to blind students. The National Federation of the Blind, for example, awards over \$70,000 a year in scholarships to worthy blind students. Contact the NFB for further details about these and other special scholarships for the blind.

Products and Aids — Technology has made many useful products available to the blind. Some aids make daily life easier (for example, the Braille watch), while others have opened up more employment opportunities for the blind (for example, talking computers). The NFB can supply information about local and national resources regarding products and technology for the blind.

For more information about any of the above programs and services, contact us at: National Federation of the Blind, 1800 Johnson St., Baltimore, MD 21230; telephone: (410) 659-9314.





Ann Terry is a registered dietitian who works at the State Hospital in Fulton, Missouri and at the Veterans Administration Hospital of Columbia, Missouri. She graciously calculates the diabetic exchanges and food values for our recipes.

Send your great ideas to the editor. He is the official taste tester and needs recipes to test his taster.

Bananas in Wine Sauce

This good-sounding recipe appeared in the April 20, 1989 issue of *New Press*, Ft. Meyers, Florida. It is from the cookbook titled *Cooking for Diabetics*.

2 medium bananas
1 tbs. unsalted margarine or butter
1 medium orange
2 tbs. sweet dessert wine (optional)
Peel bananas and slice in half, lengthwise. In a chafing dish or skillet, melt margarine or butter. Slip bananas in, sauteeing on both sides without breaking the bananas.
Slice orange and squeeze half over the bananas. When the bananas are soft and sauce begins to thicken, pour wine (if used) over bananas. Cook until alcohol evaporates. Using a spatula, transfer the bananas to plates, offering 1/2 banana with some sauce for

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Diabetics Division elects new president, brings in new board member



Ed Bryant



Janet Lee



Lorri Riddle



Bill Parker



Tom Ley

The yearly conference of The Diabetics Division of the National Federation of the Blind (NFB) took place on July 5, 1993, at the NFB annual convention in Dallas, Texas. Donovan Cooper, immediate past president, did not, for reasons of poor health, seek re-election. Donovan is a fighter, and we send him best wishes for a rapid recovery.

New division president Ed Bryant, who donates his services as Editor of *Voice of the Diabetic*, joined the Federation in 1979, and has served

on numerous committees, holding several leadership positions.

Ed Bryant was one of the 85 founding members of the Diabetics Division at the NFB 1985 convention in Louisville, Kentucky. He realized that to effectively spread the word about diabetes and blindness, the new support and information network would need a publication. He was given the job of establishing that publication, and in January of 1986, the first edition of *Voice of the Diabetic* was published, with a circulation of approx-

imately 600. Circulation has grown explosively, today reaching well over 67,000.

Ed Bryant says: *We are here to serve men and women who are blind or losing vision from diabetes, as well as anyone experiencing complications from the disease. We serve all diabetics, because everyone with diabetes is at risk of developing its side effects.*

I want diabetics to know they are not alone, and that if they are experiencing difficulties, in almost all cases practical options are available.

Of course diabetes can bring a myriad of problems, but our Diabetics Division will not do as some groups, and use scare tactics as a fundraising tool. Diabetes is insidious and can cause catastrophic problems, but it will never tell people that if they have the disease, they can EXPECT chronic complications. Our division knows that every diabetic should strive for good control to minimize and perhaps prevent complications; should maintain a positive attitude; and should live one day at a time.

I feel privileged and honored to hold the position of Diabetics Division President. I will always strive to look at the entire picture, to touch all the bases and be a good listener, while fulfilling my duties. Our organization has thousands of members, and these men and women will always receive

Board Members

The Diabetics Division of the National Federation of the Blind.

Ed Bryant, President, 811 Cherry Street, Suite 309, Columbia, MO 65201; Phone: (314) 875-8911

Janet Lee, Vice-President, 555 199th Ave. NE, Cedar, MN 55011; Phone: (612) 434-7933

Lorri Riddle, Vice-President, 402 4th Ave. E., Twin Falls, ID 83301; Phone: (208) 734-8636.

Bill Parker, Treasurer, LaFayette Tower, 4601 Mayflower Rd., Apt. 2D, Norfolk, VA 23508; Phone: (804) 623-1638

Tom Ley, Secretary, 2514 Deas St., Bossier City, LA 71111; Phone: (318) 746-0356

support and information regarding diabetes and blindness. We are all part of one big wonderful family and will work together as a team.

New Board Member Lorri Riddle, from Twin Falls, Idaho, was elected to the position of Second Vice President. Vivacious and capable, Lorri brings new blood to the Diabetics Division leadership. She is currently President of the Magic Valley chapter of the NFB of Idaho, State Coordinator for the Diabetics Division of the NFB, and serves on the State Board of the NFB of Idaho. As part of her duties, Lorri will work on special assignments with President Bryant.

Lorri says: *I consider it a big honor to be working on the national board, and I'm really looking forward to working with President Bryant and the other board members. Everybody seems very up and hardworking. It will be a good experience for me.*

Congratulations to you, Ed, for being elected President, and to you, Lorri, for being elected Second Vice President. Your positions are well deserved.

Dear friends

The Diabetes Treatment Center of Houston, Texas asked its past and present patients to comment on measures that family members or friends can take to better support the person with diabetes. Only minor editing was made to the following responses.

If you have comments that would help others better understand diabetes, please send them to the Voice editor.

• Because I am an insulin-dependent diabetic, I would like my family to observe me closely in order to notice any changes in my day-to-day activities. Thus giving me the care I need.

- I know education is extremely important so I would like to have as much information as possible about diabetes.
- I have an uncontrollable weakness to "fly off the handle" at relatively unimportant situations.
- I would like for my family members to know how they can best support me in managing my diabetes. Please understand that my blood sugar should not be too high or low. Also, know how to help me if it is too high or low.





Food for thought

We invite blurbs and tidbit articles for inclusion in this column. Materials received may be edited and used as space permits. Products and services included in this column are for information only and do not imply endorsement by The Diabetics Division of the NFB.

Voice Distributors Needed

Since the *Voice* is now offered free, our Diabetics Division will provide extra copies to anyone wanting to help spread the word. We will gladly send from five to five hundred-plus copies each quarter to be used as free literature. Medical facilities can

order as needed for patients. Individuals can usually place copies of the *Voice* in libraries, pharmacies, hospitals, doctors' offices, or other public locations.

Diabetes education is essential. Anyone who distributes the *Voice* will be helping people with diabetes, and their families, to learn about the disease and its ramifications; to learn that they have options; and that their world is far greater than whatever "limits" may be imposed by the disease. If you would like to help spread the word by distributing the publication, please contact: *Voice of the Diabetic*, 811 Cherry St., Suite 309, Columbia, MO 65201; telephone: (314) 875-8911.

Letters to the editor

(Continued from page 17)

Columbia, MO

Dear Mr. Bryant:

Recently, my work as a diabetes educator required me to find — as quickly as possible — a device that would help a blind mother measure and draw up insulin for her newly-diagnosed diabetic child. In vain, I searched locally, and, out of desperation, called the *Voice of the Diabetic* for a possible lead.

I have received your publication for several years and have passed it on to those patients with vision loss. When I called, I expected to speak to a secretary or a message machine. Imagine my surprise — and subsequent delight — to have had you answer the call and immediately provide all the information I needed.

Mother and child are doing quite well. I sincerely appreciate your taking the time to help us. Thank you very much.

Warmly,
Pat Favorite, RN, CDE
Department of Education

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Nancy J. Lake
Sarasota, FL

Voice of the Diabetic
Columbia, MO

I just read your magazine for the first time. I'm a diabetic of 31 years and I am having problems with diabetic retinopathy and charcot joint in both ankles. A fellow diabetic in a local support group loaned me your magazine. I was so impressed I wrote down your address and decided to

write to you about receiving your magazine. I also would loan it to anyone who is interested in reading it. I'm sure there are many people in our support group who will also write for your magazine. Would you please forward your magazine to me.

Nancy J. Lake

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Sue Schmidt, RN
Clermont Mercy Hospital
Batavia, OH
July 6, 1993

Diabetics Division
National Federation of the Blind
Columbia, MO

Dear Mr. Bryant,

I greatly appreciate the opportunity to distribute *Voice of the Diabetic*, and thank you for this wonderful publication.

The outreach centers for medically underserved people where I work has proven to be a great place to distribute them. I also give them to the many company representatives who donate medical supplies to us.

Could I please have some copies of your pamphlet "Diabetes, Complications, Options" to distribute to our two support groups and to place in our local physician's office? Three or four dozen or more if you are able to send that many.

Thank you and continue the good work. I am enclosing a small donation that was donated to us.

Best regards,
Sue Schmidt, RN
Clermont Mercy Outreach

Q: What is the difference between in-laws and outlaws?

A: Outlaws are wanted.

Braille Knobs and Overlays

We have been asked to announce: The General Electric Answer Center provides free Braille overlays and special knobs for visually impaired customers with GE, Hotpoint, or post-1988 RCA major appliances such as microwaves, washers and dryers, and electric ranges. This adaptive equipment is absolutely free, and may be obtained by calling the GE Answer Center, at 1-800-626-2000, open 24 hours a day, 365 days a year. Be sure you give the model and serial number of your appliance.

Braille Calendars

The American Action Fund for Blind Children and Adults is offering, free-of-charge, an attractive 1994 calendar

Voice Formats

Every year diabetes causes many men and women to become blind. If you are currently receiving the *Voice* in print and have difficulty reading it, you may receive it on cassette at no charge. Tapes are recorded at 15/16 IPS, and require a special tape player. Proper players may be obtained, free, from Regional Libraries for the Blind and Physically Handicapped, or by telephoning the National Library Service at 1-800-424-8567. If you wish to receive the *Voice* in a different format, all you need to do is contact us at the *Voice* editorial office. Some readers choose to receive the *Voice* in both formats, and there is no charge for this service. Let us know how you want your *Voice*!

What you always wanted to know but didn't know where to ask

(Resource list)

(Inclusion of materials in this publication is for information only and does not imply endorsement by The Diabetics Division of the NFB.)

New Blood Glucose Monitor

Diascan Partner: This eight-ounce audio output glucometer, which comes complete with adjustable over-the-shoulder tote bag, and an earphone for private listening, features simplicity of operation, and a clear, easy-to-understand voice. The system will announce its calibration settings, which can be changed as needed. You do not need to get a drop of blood on the center of a reagent strip pad. Blood can be smeared onto the pad and still obtain a clinically acceptable reading.

The Diascan Partner comes with both print and cassette instructions. Suggested retail price is \$399. Contact: Home Diagnostics Inc., 51 James Way, Eatontown, NJ 07724; telephone: 1-800-342-7226.

Insulin Measuring Gauges

Autopen: Designed to use Novo Nordisk's "Novolin" insulin cartridges and needles, the device comes in two models: one that clicks for each unit drawn, from one to 16 units, and the other that clicks at each two-unit increment, with a range of two to 32 units. The Autopen costs \$49.50, available from: Ulster Scientific, Inc., P.O. Box 902, Highland, NY 12528; telephone: 1-800-431-8233, or (In NY) 1-800-522-2257.

Count-A-Dose: Calibrated for use with B-D LoDose (50-unit) syringe, the device holds two insulin vials and di-



rects the syringe needle into the vials' rubber stoppers. This simple and reliable device uses a thumbscrew that clicks for each one-unit increment measured. Instructions are provided in print and cassette. The device costs \$40, available from: the National Federation of the Blind, Materials Center, 1800 Johnson Street, Baltimore, MD 21230; telephone: (410) 659-9314.

Load-Matic: Calibrated for use with the B-D 100-unit syringe, the device aligns the needle with the vial stopper, features two separate controls for loading (one for single-unit and the other for ten-unit increments), and tactile prompt to confirm dose setting. Some problems have been reported with the device: the instruction cassette has few references to tactile landmarks; the zero-prompt on the one-unit scale is hard for individuals with neuropathy to access; it is easy to unintentionally short-stroke the ten-unit loading lever and draw an incomplete dose. The device costs \$49, available from: Palco Labs, 8030 Soquel Ave. #104, Santa Cruz, CA 95062; telephone: 1-800-346-4488.

Novo Pen: The device resembles a fountain pen, and requires purchase of special insulin cartridges R, N, or 70/30 mixture. The nickel and brass Novo Pen clicks for each two units of insulin drawn, with a range of two to 36 units. The device does not permit insulin mixing; two injections would be necessary. Novo Nordisk's less expensive "Novolin Pen" lacks any audio or tactile prompts, and depends on a visual scale for measurement. The Novo Pen's suggested retail price is \$99, available from: Novo Nordisk Pharmaceuticals, Inc., 211 Carnegie (Continued on page 20)

What you always wanted to know but didn't know where to ask

(Continued from page 19)

Center, Princeton, NJ 08540; telephone: 1-800-727-6500.

Syringe Support: Designed for use with the B-D 100-unit syringe, this inexpensive Canadian import loads with a wheel atop a screw-threaded shaft. Each full turn of the wheel measures two units, with a raised ridge as marker and tactile prompt. One half-turn will draw a single unit, but there is no prompt to let the user know that a half-turn has been reached. The device lacks any click-prompts, and is of most utility to those who must measure doses greater than 10 units. The instrument costs \$14 (U.S.), available from: Foundation Centre Louis Hebert, Inc., 525 Boulevard Hamel-Est, Aile J, Quebec, Quebec, Canada, G1M 2S8; telephone: (418) 529-6991.

Computer Equipment

Aicom Accent Text-To-Speech Synthesizer: Converts text on your computer screen to speech, with vocabulary of over 20,000 words. Eight models: full-length (\$745) or half-length (\$545) PC plug-in cards for IBM PC-compatibles; cards for Toshiba laptops T1200, T1600 (\$395) or T1000SE (\$675); plug-in card for Microcrochet PS/2 (\$745) or stand-alone unit with RS-232C link to any computer (\$995); plug-in card for Toshiba T1200XE, T2000SX Laptop plug-in card (\$675), and more. Supported by all major screen-reader programs. Contact: Aicom Corp., 1590 Oakland Road, Suite B112, San Jose, CA 95131; telephone: (408) 453-8251; fax: (408) 453-8255.

RX Program

Advantage Health Services offers the RX Freedom Advantage Program. This service, open to anyone with major medical insurance coverage, provides direct shipping of prescriptions, home health and diabetes supplies, and equipment, and direct billing of your insurance carrier. Advantage handles all paperwork, and accepts the standard insurance 80% as payment in full. For information contact: Advantage Health Services, Inc., 802 S. York Road, Hatboro, PA 19040; telephone: 1-800-682-8283.

Test Strips

Biotel Inc. manufactures an inexpensive line of glucometer test strips. Their products, Hi-Value 3 and Hi-Value 5, work exactly like other strips at lower cost. Biotel states their 50-strip packages should cost \$23 or less. For further information, call Biotel at: 1-800-445-4551.

Cookbooks

The Equal Cookbook: contains recipes assembled without added

sugar. Available free, on cassette, in large print, or in Braille, from: The NutraSweet Co., Box 830, Deerfield, IL 60015; telephone: 1-800-323-5316.

Fascinating Free Food for Fun and Family Feasting: a combination of 45-minute VHS videotape and 56-page bold-print (slightly larger than standard) cookbook, of recipes developed for people with diabetes, heart disease, or weight-reduction diets. The package costs \$49.99, available from: Charleston Area Medical Center, Diabetes Center, 3200 MacCorkle Ave. S.E., Charleston, WV 25304; telephone: (304) 385-555.

The Microwave Times: a bimonthly magazine of recipes, cooking tips, and recommendations, available on cassette or in standard print. Although readers will find many useful hints in this magazine, some recipes are inappropriate for a diabetic diet. Cassette

subscription (one year) costs \$31, available from: C.L. Productions, Visually Impaired Ltd., 3225 N. Hwy. 67 No. H2, Mesquite, TX 75150; telephone: (214) 681-2771. Print subscription (one year) costs \$11.95, available from: *The Microwave Times*, P.O. Box 1271, Burnsville, MN 55337-0271; telephone: (612) 890-6655.

The All New Cookbook For Diabetics and Their Families: with over 200 recipes and an exchange list. All

recipes were prepared by registered dietitians at the University of Alabama Hospital. The book also offers exchanges for fast foods, a nutrition guide for diabetics, charts for sugar substitutes/exchanges, and a section to help diabetics understand how to eat on "sick days." Cost is \$12.95 plus \$2.99 shipping. Available in standard print only from: Oxmoor House, P.O. Box 832463, Birmingham, AL 35201; telephone: (205) 877-6000.

ADVERTISERS

Effective advertising doesn't scream at its audience. It persuades. It sells. The key to cost-effective advertising is making your voice heard where an audience is already listening. *Voice of the Diabetic* offers such an outlet. Make your voice heard. For advertising information contact:

Voice of the Diabetic
Ed Bryant, Editor
811 Cherry Street, Suite 309
Columbia MO 65201
(314) 875-8911

Subscription/Donation Form

The *Voice of the Diabetic* is a quarterly magazine published by The Diabetics Division of the National Federation of the Blind (NFB) for anyone interested in diabetes, especially diabetics who are blind or losing vision. It is an outreach publication emphasizing good diabetes control, diet and independence.

Donations are gladly accepted and appreciated. Contributions are not only tax deductible but are needed to keep the *Voice* and the Diabetics Division moving forward to help people with all aspects of diabetes.

Members of the NFB Diabetics Division enjoy priority services and unique benefits such as a continuous free subscription to the *Voice*, automatic access to committees covering all aspects of diabetes, free counseling concerning all facets of blindness and diabetes as well as access to diabetics who have experienced complications.

The *Voice* is free to any interested person upon request. Each subscription costs the Diabetics Division approximately \$20 per year. To help defray publication expenses, members are invited, and nonmembers are requested, to cover the subscription cost.

To begin receiving the *Voice*, please check one:

I would like to become a member of the NFB Diabetics Division and receive the *Voice of the Diabetic*. (Members are entitled to special membership benefits.)

I would like to receive the *Voice of the Diabetic* as a nonmember. (Nonmembers are encouraged to pay the institutional rate of \$20/one year; \$35/two years; \$50/three years.)

Send the *Voice* in (check one):

print cassette tape for the blind and physically handicapped (recorded at slower-than-standard speed of 15/16 IPS) both

Optionally check this box:

I would like to make (or add) a tax-deductible contribution of \$ _____ to The Diabetics Division of NFB.

Please print clearly

Name _____

Address _____

City _____ State _____ Zip _____

Telephone (_____) _____

Send this form or a facsimile to:
Voice of the Diabetic, 811 Cherry St., Suite 309, Columbia, MO 65201

Please make all checks payable to:
NATIONAL FEDERATION OF THE BLIND